# *There's No Place Like Home - A Cost and Outcomes Analysis of Alternative Models of Care for Young Children with Severe Disabilities in Ireland -*

## New report launched today endorses the Jack & Jill homecare provision for sick children, recommends more State funding for home nursing care & an extension of Jack & Jill's service to support children up to the age of six years old

(Wednesday 3rd February 2010) According to a new report launched today in Buswells Hotel in Dublin and online at www.jackandjill.ie, the average annual costs falling on the State to deliver acute hospital care for a severely disabled child are estimated to be €147,365 – almost nine times higher than the average cost of €16,422 per child for the homecare provision currently supported by the Jack & Jill Children's Foundation. Entitled "There's No Place Like Home - A Cost and Outcomes Analysis of Alternative Models of Care for Young Children with Severe Disabilities in Ireland" and written by the Centre for Health Policy and Management at the School of Medicine in Trinity College Dublin, the report surveys Jack & Jill's families nationwide and examines international evidence on the alternative models of care for severely disabled children. It recommends that the State increases its financial contribution to the Jack & Jill Foundation to ensure the sustainability of services which will achieve a net saving for the public purse. The Foundation currently receives only 19% of its funding through the State and raises most of the €3 million budget it requires annually through the recycling of mobile phones – a situation which, according to Jonathan Irwin, Founder & CEO of Jack & Jill, is "unsustainable longer term no matter how many mobile phones we collect". The report also recommends that the HSE fill the estimated €1,970,640 per annum financing gap to enable the expansion of Jack & Jill's provision to children up to the age of 6 years old - the age at which children begin to receive care through expanded government programmes, rather than cutting off the service at the age of 4. Jonathan Irwin, CEO of the Jack & Jill Foundation said today that, "What makes the Jack & Jill model work is that we start off with the needs of the child and the family and we design the home nursing care model around that. We're keen to get into a 50/50 partnership with the HSE in relation to funding Jack & Jill over the next 5 years which makes financial sense, as well as being the right thing to do and to extend our service to support children up to the age of 6, because that's what our families need. Now that we have this report, our priority is to get into see the real decision makers in the HSE and the Department of Health & Children within the next 6 weeks." The Jack & Jill Foundation, an Irish children's charity established in 1997 by Jonathan Irwin, has supported over 1,200 families nationwide with home nursing care and respite for children up to the age of 4 years old who are born with or who develop brain damage and who suffer from severe intellectual and physical developmental delay as a result.

According to the report, "Statutory homecare, provided by the State, is highly variable" and the report highlights the enormous strain, worry and distress for families of having a child in serious ill health, which, it says, is compounded by massive financial losses. It highlights that annual direct costs per child falling on families are estimated to be €22,261 for hospital care and €2,620 for Jack & Jill provided homecare, with the main cost-drivers behind the large difference being family accommodation, parking and food requirements when a child is in hospital. It states that annual indirect costs falling on families which represent lost income generating opportunities through the care of a disabled child also place an enormous financial burden on families irrespective of the model of service delivery. It says that "The early years of life are a stressful time, not only for the child, but also for his or her parents. Successful models of care must therefore support not only the well-being of the child, but also the well-being and functioning of the broader family." It also states that while the Jack & Jill homecare model receives a much greater satisfaction rating than the other service models, families worry about their child's support structure as the children get older and it recommends the extension of the Jack & Jill service to support children up to the age of 6 years old.

According to Jonathan Irwin, who dedicated the report to his son Jack, “Caring for Jack at home over his short life taught us a great deal and we vowed that no other parents should have to face this nightmare alone and that’s why we set up the Jack & Jill Children’s Foundation in 1997. Today, this report is a strong endorsement of our service. However, it’s time to reinforce our financial backing to make Jack & Jill more sustainable and less reliant on mobile phone recycling and we want to extend our service to support our children up to the age of 6 because that’s what our families need. However, rather than looking for a handout from the HSE, we demonstrate a proven care model that is cost effective and efficient and saves the taxpayer money by keeping our children at home rather than in hospital beds but this model needs more State funding.”

Eddie Hobbs, who is the Patron of Jack & Jill, added that, “If Jack & Jill ceased to exist tomorrow and 50% of the 291 children it supports today with home nursing care went into hospital that would cost the State over €410,000 per week – which just proves the financial saving of the Jack & Jill model. Therefore, it makes sense for the State to invest more in Jack & Jill as it pays dividends for the families, for the HSE and for the tax payer.”

For the past 13 years, the Jack & Jill Children’s Foundation has provided frontline homecare and respite services to families of children who are born with or develop brain damage and who suffer from severe intellectual and physical developmental delay. Since 1997 the Foundation has supported over 1,200 families by providing home visits, practical advice, emotional support, information and guidance to access the range of additional assistance available, bereavement support and funding for up to 80 hours of home nursing care per month for children up to the age of 4 years old. The report notes that “Jack & Jill provision is based upon the strong belief that homecare, within a supportive community, is the best model for both children and their families.” These families refer to the Jack & Jill support model as “The gift of time – time to do those normal things that others take from granted, like sleeping, shopping, spending time with the other siblings, with the peace of mind that their sick child is being well cared for.”

Jonathan Irwin and his wife Mary Ann O’Brien (MD of Lily O’Brien’s Chocolates) established the Foundation based on their own experience with their son Jack who was born a healthy baby on 29th February 1996 but, following some invasive trauma, Jack’s brain was damaged and he could not swallow, was blind and deaf and needed a mix of drugs, physio, postural drainage, reflux operations, gastrostomy and suctioning. At that time 14 years ago, there were no services for Jack and his parents were advised to pack his little bag and abandon him at one of the children’s hospitals in Dublin. They refused and instead brought Jack home where he was cared for and loved by his family and friends until he died 22 months later.

Ends.

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